

EMPIRICAL STUDIES

Patient participation: A qualitative study of immigrant women and their experiences

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Abstract

Patient participation in healthcare is a neglected area of interest in the rather extensive amount of research on immigrant so-called Selma patients in Swedish health care as well as worldwide. The aim is to explore the phenomenon “patient participation” in the context of the Swedish health care from the perspective of immigrants non-fluent in Swedish. A phenomenological lifeworld approach was chosen. Data were collected from patients within a municipal home care setting in Sweden. Eight women agreed to participate. In seven interviews, an interpreter was necessary for the translation of the interview. Five authorized interpreters were used. Data were analysed in accordance to a descriptive phenomenological method for caring research. The analysis led to an essence of the phenomenon with three constituents, “to experience participation,” “to refrain from participation,” and “to be deprived of participation.” Patient participation from the perspective of immigrant women means that patients are involved and active in their own health and caring processes. For these women, it is particularly important to have the opportunity to express themselves. Patient participation presupposes professional caregivers who act in a way that increases the patients’ opportunities to take part. A skilled interpreter is often necessary in order to enable the patient participation.

Key words: *Immigrants, patient participation, phenomenology, translating, women*

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Introduction

During the latter half of the 20th century and the beginning of the 21st, immigration to Sweden increased and Sweden can now be described as a multicultural society. Variations over time concerning both the number of immigrants and the countries of origin are substantial. From the 1970s and onwards, labor immigration has been replaced by refugee immigration, which reflects global war and unrest. At the beginning of the 21st century, non-natives represented approximately 12% of the total population, or 1.1 million people (Ekberg, 2007).

When the occurrence of ill-health is compared to ethnic Swedes and those living in Sweden with an immigrant background, there is an obviously higher risk of contracting ill-health for immigrants. To some extent, this can be explained by the general living

standard in the immigrants’ native countries or experiences of war or persecution (Vogel, 2002). In Sweden, it has also been common for labor immigrants to have physically hard jobs, which may affect their health negatively. Yet another explanation is the occurrences of segregation and marginalization in society (Groglopo, 2006).

In Sweden as well as in Finland, UK, and the US, health care legislation emphasizes the importance of patient participation when care is planned (Eldh, Ekman, & Ehnfors, 2006). For example, this means that professional caregivers are responsible for information that enables patients to form an opinion of advices and to participate in decisions.

However, such participation does not always go without saying. Ashworth, Longmate, and Morrison (1992) found a number of factors that seem to determinate patient participation in care, for example

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a common knowledge base, a carer who adapts to the patient's problems, that no one's identity feels threatened, and to pay attention to views of relatives. Cahill (1996) takes this one step further and claims that a caring relation is a prerequisite for patient participation. Furthermore, Cahill claims that caring relations are important in order to place professional caregivers' knowledge at the patient's disposal. Thus, the meaning of patient participation includes partnership, collaboration, and involvement. To some extent, Cahill's conclusions are supported by Eldh, Ehnfors, and Ekman (2004) and Eldh et al. (2006) who found that hindrance for patient participation in literature is described as a lack of respect for patients' needs, lack of information, and inadequate interpersonal relations of patients and the health care staff. In addition, inadequate social support and difficulties due to language obstacles decrease patients' opportunities to participate in their own care (Andershed, 1999; Eldh et al., 2004, 2006).

Hence, obstacles for participation may arise when a patient with immigrant background does not speak the same language as his or her caregiver(s). Such problems have been investigated in several studies (see for example, Gerrish, Chau, Sobowale, & Birks, 2004; Ozolins & Hjelm, 2003; Thyli, Althin, & Hedelin, 2007). According to Elder (2003), knowledge in the second language also gives better access to medical care. Moreover, caregivers often fail to understand the patient's needs when they do not share their language (see for example, Gerrish, 2001; Murphy & MacLeod Clark, 1993).

Participation in care planning

The general possibilities for patients to participate in care planning and performance have been studied in different contexts. However, most studies have been focused on professional caregivers' rather than the patients' own experiences in patient participation (Eldh et al., 2006; Jewell, 1994; Sahlsten, Larsson, Lindencrona, & Plos, 2005). In fact, patient participation as an involvement in the process of health and care and its relation to well-being from the perspective of immigrant patients seems to be virtually non-existent in literature.

At first, it seems reasonable to assume that language obstacles negatively influence the possibilities to participate when planning caring interventions. The ability to share one's experiences, to profit from information and to acquire new knowledge demands fluency in the caregiver's language. Unfortunately, the opposite often seems to be the case, especially if the patient with immigrant background has reached a high age.

The present study directs interest to immigrant women in Sweden. The focus of the study is their experiences of obstacles and possibilities for patients' participation in their own care once they become patients in the Swedish health care. Thus, it is important to investigate the phenomenon "patient participation" when the patient has limited access to the language of the caregivers. Therefore, the aim of this study is to explore the phenomenon "patient participation" in the context of the Swedish health care from the view of immigrants non-fluent in Swedish. The specific research question is: What does patient participation mean to immigrants within a Swedish health care context?

Method

The design of the study is a phenomenological lifeworld approach. Lifeworld-based research is focused on the world as it is experienced prior to the formulation of any hypothesis in order to explain it (Dahlberg, Dahlberg, & Nyström, 2008). In this study, a meaning-oriented phenomenological analysis was used in order to understand the lifeworld of immigrants with experiences of homecare in Sweden (Dahlberg et al., 2008).

Participants

The participants were selected from a municipal home care setting in Sweden. The inclusion criteria were immigrant men and women with home care, aged 18 years or older. The exclusion criteria were forensic psychiatric care and severe mental illness.

None of the men agreed to participate but eight women aged 54–89 years wanted to participate in the study and agreed to be interviewed. Only one of them spoke Swedish, although with some difficulties. In the other cases, the collection of data depended on an interpreter. Hence, five authorized interpreters were contacted to interpret seven interviews.

All the women had migrated during the 1980s and 1990s from Eastern Europe and the Middle East region. Only two had had an employment in Sweden. Before each interview, the interviewee or her next of kin was asked about her native language and dialect. This procedure made it possible to reserve an authorised interpreter in the specific language, and in some cases, to precise the dialect. The interpreters were informed of the research, the method for data collection and that the interpretation should be verbatim.

Data collection

The interviews were conducted in the interviewees' homes by the first author (EBB). The interpreter was seated beside the interviewer with the interviewer face-to-face with the interviewee. The interviews were conducted in the form of a dialogue, and the interviewees were encouraged to talk openly about the experiences of the phenomenon (cf. Dahlberg et al., 2008). The first question posed to each participant was to describe how they generally experienced the visits of the home care team. This initial question aimed at inviting the interviewees to recall and reflect on their experiences. In order to focus the interviews on patient participation, the initial interview question was supplemented with follow-up questions such as, "Can you explain it more?" or, "What did you think about that?" when the interviewee talked about issues that could be related to patient participation. The interviews were audio-taped, lasted 30–60 min and were transcribed verbatim.

Data analysis

The data analysis followed the descriptions by Dahlberg et al. (2008). In such analysis the intent is to go beyond given conditions, avoiding linear or causal explanations. Based on an understanding of the data as a whole, attention was directed toward its diverse meanings related to the phenomenon. Meaning units were identified in each interview. When each interview had been scrutinized, all meanings were searched through for similarities and differences in order to see any pattern of meanings. Particular attention was directed toward essential meanings that could say something general about the phenomenon patient participation. However, the individual meanings were not abandoned but described in three constituents that together with the essence description constitute the full meaning structure of the phenomenon. It is also important to emphasize that all meanings, also the essential ones, are understood as contextual, and therefore, no meaning can be seen as finite or universal.

Ethical considerations

The research design was approved by the Ethic Committee at the Sahlgrenska Academy, University of Gothenburg (S 241–02). However, due to the language obstacles it was not always possible to follow the plan exactly as the ethic committee had approved. For example, the participants did not understand the written information about the study. Therefore, it was orally described by the interpreter before the interview. The translation was followed by

information about their voluntary participation and that it was possible to withdraw at any time. The interviewees were also informed about confidentiality and that the interviews should only be used as data in a study. After this procedure, written informed consent was obtained from all interviewees.

Results

The essential meaning of patient participation describes how immigrant female patients are involved in their health and care processes. Their participation in the healthcare is more or less insufficient, which does not only say something about the health care approach but reflects their general deficient participation in the Swedish society. Experiences of weak societal participation become explicit when health issues are approached.

Compared to findings from studies with non-immigrant patients, there are no essential differences besides the problems caused by language deficits. Thus, there are more individual differences than group differences. The particular nuances of the experience of participation can be related to the deficient societal participation and language obstacles. It is hard to grasp the Swedish ways of living and participating in health care.

Furthermore, even immigrant patients' participation includes more than merely being informed, more than being able to read hospital records and examination results, and more than merely being given the opportunity to choose from a few treatment options. For patients, participation essentially means to be the true focus of the care, to be listened to and be taken seriously. For these immigrant patients, it is particularly important that they are given the opportunity to express themselves and that the caregivers are ensured that they have understood the given messages.

To experience participation

Participation occurs when patients have the opportunity of expressing their needs and feel enthusiastic. Feeling free to make requests is essential for this experience. This means that caregivers need to listen to and enable patients to be involved in their care situation. The women in our study talked about the need of attracting attention and to be taken seriously by their caregivers. This is not only valid for the care situation but seems to go beyond the manifested situation, which confirms the women's general sense of self-determination.

To feel free to make requests and be adequately treated seems to be a prerequisite for participation in the encounters between patients and caregivers. However, this is not something static but differs

with the patient's health status. One of the interviewed women was anxious about getting pain relief when it was needed:

Because I can tell you about my symptoms I can take part in the decisions. These days when I do not feel well, I can tell my caregivers that extra [pain relief] is needed. The days when you can tell what you want and what you need, these are the days when you make the decisions.

For patients, participation is of vital importance in order to encounter openness, i.e., an open and "hearkening" caregiver stance. Essentially, the informants expressed the importance of being understood as an individual and not merely as the representative of a homogenous group of immigrants. Equally important is that non-verbal communication is understood and taken as seriously as spoken words. If words are missing out, body language, for example, eye contact, can express deep feelings if enough time is given.

The meaning of an open attitude can be described as a respectful relationship between patients and caregivers. One of the women expressed that there is a feeling of participation when

I am not feeling like a stranger to the caregivers, it feels like I am with my people or relatives. When you respect each other, you are happy. (I: How does this affect you?) If I feel emotionally unwell and my caregivers come here and talk to me in that special way, I feel better. (I: What do you mean?) I am an old woman with a disease. When the caregivers talk with me I can feel that I am not longer unwell. They respect me.

To provide participation for immigrant women non-fluent in Swedish, language obstacles must be overcome in one way or another. The interviewed women's ability to understand Swedish was strongly limited. With the presence of an interpreter, it was possible for them to communicate their needs, what they wanted and how they were feeling. They described such a support as a prerequisite for asking questions and get answers from their caregivers. One example of another hindrance, although not as explicit as insufficient language skills, is the patients' tiredness or pain. One of the interviewed women talked about the importance of caregivers confirming that they did understand what she said:

"I was very weak and only said a few word, yet the caregivers understood what I said." I asked, "How do you understand what I say?"

and they answered that they understand all that I said. That was a confirming message.

To refrain from participation

For different reasons, the women accept lack of influence and involvement in their own care. There also seems to be an acceptance in not knowing what the caregivers are talking about. The interviewed women did not demand a total understanding but accepted an inadequate communication. As a result, the patients were not invited as an active part of a caring relationship but were passively receiving whatever care was offered, in whatever way.

It may serve the caregivers' workload when the patients accommodate themselves to the prevailing situation. The women in the study knew that the caregivers had to visit many other patients, and as a consequence they complied with the caregivers' decisions. One of the women described that once she gets well, she will be able to relieve the caregivers by having one patient less. Thus, what she does best is cure her wounds, which means that she does not have to ask for their help anymore.

In relation to the patients' experiences of the caregivers' work situation and the decreasing demand for qualitative care, patients merely subject themselves to the caregivers' decisions. One example of this is the uncertainty of not knowing when or which caregiver is coming to one's home. Even though the women cannot control these visits, this is still of great value. They refrain from participation but are happy with caregivers coming at all, so in another way the caregivers are seen as experts on the patients' health situations.

Even if we can not talk to each other, it is good. I have been here for ten years and through the years I have been in contact with doctors and nurses. We know each other nowadays. And, as you can see, every nurse knows what to do. When the nurse is here, she prepares my medicine. When the caregivers are here in my home they all do in the same way.

To refrain from participation includes being modest and show total compliance. One meaning of this is the experience of vulnerability and uncertain situations, but it could also mean a sheltered situation, which, in that way, is safe. The patients assume that the caregivers do their best and that they have enough knowledge and devotion to do a good job. Problems arise when the two parties are of opposite opinions. Uncertainty may arise when patients are in conflict with their own perceptions but still join care assessments and decisions about their own health. One of the interviewees explicitly expressed how she

always agrees with the caregivers, even when they do not ask her what she wants. As a consequence, she has never had to take any decisions of her own. Yet, she stresses the importance of the caregivers agreeing with each other. If this does not happen, she may face serious troubles.

To be deprived of participation

While the non-participation described above is subtle, one explicit meaning of non-participation is when a patient is deprived of participation. The interviewed women described that they felt overlooked and objectified as well as offended and insecure in the healthcare system. Their obvious dependency on caregivers entails the fact that the women do not see other alternatives than accept the situation.

Women deprived of participation experience that they feel treated like a “thing” among other things. To be an object instead of a living individual makes it difficult to take an active part in recovering. This leads to difficulties for them to maintain an inner image of deep and profound knowledge in themselves. When their own lived experiences differ from that of the caregivers, this knowledge is pushed aside and they silently accept to be viewed as a “bunch” of bodily symptoms. However, their suffering is not necessarily as silent as it may sound:

One day a doctor and a nurse visited me. They did not ask about anything, they wrote down notes and then went away. That day, when I am not asked about anything or I am not allowed to make own decisions, how do you think that feels for me? The visit only resulted in new medicines. Why didn't they tell me? I was disappointed and wondered why they did not inform me. That day I got disappointed and annoyed. Because of my illness, they did not ... take me seriously. That made my symptoms worse; my suffering increased.

The women told us about deep insecurity with the healthcare services, for example a sense that the caregivers are insecure in their actions. Generally, caregivers who do not consider patients worthy of participation do not bother to respond to their questions, which might result in serious consequences. One of the informants described how she was allergic to penicillin, of which she always had informed her caregivers, but in spite of this she had an intravenous injection of penicillin. When she did not manage to make herself understood, she cancelled the injection and called on the nurse. Since

then, her trust in caregivers' competences is not to be taken for granted.

To be excluded from the ability to understand and make oneself understood also means not to be involved in the health-regaining process. This is particularly problematic when no one is present to interpret between patients and caregivers. In addition, caregivers must be trained in not viewing the patient as a person without a history of his/her own. This is clearly revealed when the interviewees talked about caring situations when there were no interpreters present, which means that they had few opportunities to express their symptoms or needs. Sometimes it is not even possible to express one's basic needs or have them regarded:

I could not ask for water. It was very difficult. I tried to explain that I wanted a glass of water. But there was one woman who finally understood me, she helped me. She also had been a patient.

Being a patient in such circumstances entails a high level of dependency on caregivers. Not experiencing oneself as part of a caring relationship makes patients feel offended. They are at the mercy of the caregivers' skills to bridge language obstacles and provide them with insightful care. The interviewees had not told the caregivers that they felt offended. Instead, it was obvious how they silently accepted suffering, due to exclusion and non-participation in their own care.

Discussion

The findings reveal how immigrant female patients are involved and active in their health and care processes. We see several patterns of meanings that show what ought to be there in order for patient participation to exist and meet the requests of the patients. We also see how patients adapt to a pre-determined caring system without making claims on the caregivers' responsibility to ease their suffering. Accordingly, there is a tension between participation and non-participation. According to Dahlberg, Todres, and Galvin (2009), true participation means lifeworld-led care, which is more than merely patient-led care. Carers that are, “open to the lifeworlds of their patients, to listen to their stories, to touch and be touched, without avoiding the ambiguities of existence” have the opportunity to open up for patient participation, and as a consequence, a sense of coherence (p. 8). Patients who do not share their caregivers' and the surrounding society's language are extremely vulnerable in the health care and medical services system. When these patients are not enough attended to or even ignored by their

caregivers, they become blocked from every sense of coherence. Consequently, feelings of loneliness are close at hand, as is shown by Dahlberg et al. By denying patient participation, caregivers can add to the already weak sense of coherence and deficient societal participation, and contribute to experiences of existential loneliness in immigrant women.

One practical consequence of our study is that care for women who need to break isolation and get in contact with their carers as well as the surrounding society must have an interpreter involved for translating between the patient and her caregivers. If so, these women may become involved in something more than a language struggle and be able to put energy into other aspects of patient participation, such as to be listened to and be taken seriously, which from the findings emerged as essential.

Our findings show that participation occurs when patients feel free to make requests and when the carers listen to them with an open and “hearkening” attitude. The lifeworld sensitive approach confirms that these women’s senses of self-determination involve a sense of control, which is essential for experiencing patient participation. These findings add an additional meaning to this, but generally they agree with recent studies on patient participation, which is described as an experience of feeling involved in one’s own health processes. This seems to improve the patient’s sense of well-being (Johansson & Ekebergh, 2006). Participation occurs when the information provided is based on individual needs, i.e., when a patient is regarded as an individual being (Eldh et al., 2006; Penney & Wellard, 2007). One important condition for patient participation is a permissive atmosphere with emotional response from the carers (Larsson, Sahlsten, Sjöström, Lindencrona, & Plos, 2007). Such interaction has had an impact on patients’ satisfaction with the provided care (Johansson & Ekebergh, 2006; Schuster, 2006). Others have pointed to the importance of understanding and respecting the patient’s feelings and needs, especially in relation to patients, who are in vulnerable situations. Schuster (2006) says that the patient is given a new sense of status when seen by his/her caregivers, which has to be regarded in relation to the hierarchical health care system.

When caregivers describe their conceptions of patient participation, they are often aware of their power in offering opportunities for participation (Frank, Asp, & Dahlberg, 2009). Patient participation is initiated and decided by the caregiver, which can be interpreted as an authoritarian approach that threatens true participation in the care. As Sahlsten et al. (2005) claim, the caregivers’ ability to reflect on their care and attitudes is essential for

promoting patient participation. Our findings confirm that it is on the caregivers’ behalf to remove language obstacles, for example by communicating via an interpreter. Furthermore, the caregivers have to ensure themselves that the patient have understood the given messages.

However, patients can also contribute to initialize participation. Larsson et al. (2007) show that from a declared patient perspective, participation is influenced by attitudes and expectations. Patients emphasize the importance of collaboration in order to improve participation. Thus, we can conclude that patient participation can be put to play by both caring parties, but due to their professional expertise in caring, caregivers have an extra responsibility.

In a lifeworld research study, trustworthiness is achieved when openness and sensitivity are applied to the phenomenon in focus (Dahlberg et al., 2008). The aim of this study was to explore the phenomenon patient participation in Swedish health care from the perspective of immigrants non-fluent in Swedish. Hence, a phenomenological approach was suitable. The aspect of transferability of a study is whether the results can be transferred to other settings. This is supported by the authors’ description of the participants, context, data collection, and analysis in order for the readers to appraise its applicability onto other contexts. However, phenomenological researchers do emphasize the importance of varying data. The fact that no men wanted to participate in the study makes the transferability of the findings limited to immigrant women non-fluent in Swedish. Gender differences would need to be further considered.

Our belief is that the participants strived to communicate and share their experiences. However, it was difficult to reach depth in the data collection process due to the fact that interpreters translated during the interviews. For example, it was impossible to tell when an interviewee had related to an important episode. In order to concentrate on what the interviewee expressed, the first author tried to reconnect this to previous statements.

Five interpreters translated the interviews. Wallin and Ahlström (2006) claim that if possible, the same interpreter should conduct all interviews of a study in order to maintain trustworthiness. As a consequence of the variation in the women’s origin, this was not possible in our study. In addition, it is important to know that the different dialects of a language might require more than one interpreter. This study shows that it is almost impossible to reduce the number of interpreters, as could be suggested.

In addition, trustworthiness is dependent on the skills of the interpreters. In this study, we have

chosen authorized and skilled interpreters. All of our interpreters were authorized by The Legal, Financial, and Administrative Services Agency in Sweden. They all had previous experiences in translating interviews between patients and health care staff. Hence, we regard their competence as sufficient. Furthermore, the quality of the interpretations can be assessed if another interpreter listens to the tape-recorded interviews.

Implications

Some implications for health care can be described from our new insights:

- Health care and medical services are important for patients' sense of coherence and involvement in the healthcare system as well as society as a whole. In the caring relationship, the caregivers should act in a way that increases the patients' opportunities to participate in society.
- Immigrant patients are not to be treated as a homogenous group of people since they all have different needs for participating in their care.
- Patients who do not share the language of the majority of the population are extremely vulnerable in their health care, and more attention must be paid to this.
- By denying patient participation, caregivers can contribute to experiences of loneliness in immigrant women.
- Skilled interpreters must be employed in order to enable patient participation for patients who do not speak the language of the majority of the population.

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